

HIV status disclosure in the workplace

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HIV Status Disclosure in the Workplace: Positive and Stigmatizing Experiences of Health Care Workers Living with HIV

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We explored workplace experiences of 10 health care providers with HIV in the Netherlands. We used semi-structured interviews to discuss motivations for disclosure and concealment, reactions to disclosures, the impact of reactions, and coping with negative reactions. Reasons for disclosure were wanting to share the secret, expecting positive responses, observing positive reactions to others, wanting to prevent negative reactions, and being advised to disclose. Reasons for concealment included fearing negative reactions, observing negative reactions, previous negative experiences, having been advised to conceal, and considering disclosure unnecessary. Positive reactions included seeing HIV as a nonissue; showing interest, support, and empathy; and maintaining confidentiality. Negative reactions included management wanting to inform employees, work restrictions, hiring difficulties, gossip, and hurtful comments, resulting in participants being upset, taken aback, angry, depressed, or feeling resignation. Participants coped by providing information, standing above the experience, attributing reactions to ignorance, seeking social support, or leaving their jobs.

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Key words: coping, disclosure, HIV, Netherlands, stigma, work

Due to improvements in the treatment of HIV, people living with HIV (PLWH) are currently as employable and able to work as uninfected people. However, misconceptions about productivity as well as workplace stigma continue to limit PLWH's opportunities at work and contribute to nondisclosure of HIV status at work (Worthington, O'Brien, Zack, McKee, &

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Oliver, 2012). In the study reported here, we explored the workplace disclosure experiences of health care providers living with HIV in the Netherlands. Specifically, we explored motivations for disclosure and concealment at work in the health care sector, reactions to disclosures, the impact of those reactions, and the ways in which health care providers with HIV coped with negative reactions to their HIV status at work.

Background

People who possess a concealable identity, defined as an identity that is not visible to others, are able to decide whether or not to disclose or conceal that identity to others (Pachankis, 2007; Stutterheim, Bos, et al., 2011). Disclosure can have significant advantages. It increases congruency between one's private and public identity, which is associated with greater self-worth and self-esteem (Pachankis, 2007). It also contributes to physical well-being if it alleviates the negative physical repercussions of inhibition associated with keeping a secret (Chaudoir, Fisher, & Simoni, 2011). Concealment, in contrast, can be cognitively burdensome, particularly in situations where the concealed identity is salient, and the risk and costs of being discovered are great (Obermeyer, Baijal, & Pegurri, 2011). Concealment has thus been linked to increased psychological distress and lower self-esteem as well as social anxiety and isolation (Pachankis, 2007; Quinn & Chaudoir, 2009). However, it is not the case that disclosure is always the better choice. Research has shown that, for some concealable identities, particularly those subjected to significant stigmatization such as HIV, the costs of disclosure may be greater than the costs of concealment (Stutterheim, Bos, et al., 2011; Stutterheim, Bos, Shiripinda, et al., 2012; Stutterheim et al., 2009).

In the Western world, HIV is a chronic medical condition that nonetheless remains stigmatized as a result of its association with behaviors often considered to be norm-violating, such as sex between men, having multiple sex partners, commercial sex work, and intravenous drug use (Stutterheim, Bos, van Kesteren, et al., 2012). HIV is also often construed as contagious and severe, and those who have HIV are frequently considered personally

responsible for having acquired HIV (Stutterheim, Bos, van Kesteren, et al., 2012). A large body of research has demonstrated that disclosure of HIV status can lead to stigma that subsequently has substantial costs for psychological, social, and physical well-being (Stutterheim, Bos, et al., 2011; Stutterheim, Bos, van Kesteren, et al., 2012; Stutterheim et al., 2009). However, even with stigmatized identities such as HIV, disclosure may still be beneficial, as it is associated with greater self-acceptance and is key to acquiring social and instrumental support (Chaudoir et al., 2011; Pachankis, 2007). Disclosure of a concealable stigmatized identity such as HIV is also linked to decreases in anticipated and internalized stigma (Tam, Amzel, & Phelps, 2015), and can change society's beliefs and attitudes about the condition, thereby contributing to the reduction of public stigma (Chaudoir et al., 2011; Obermeyer et al., 2011).

Disclosure of any concealable identity, including HIV, is often a gradual process that entails disclosing to increasingly more people over time. As such, disclosure is often selective and starts with significant others before moving to more peripheral social contacts such as acquaintances and colleagues (Dima, Stutterheim, Lyimo, & de Bruin, 2014; Obermeyer et al., 2011).

The workplace is a unique setting in which disclosure of a concealable identity such as HIV can occur as it carries with it unique advantages and disadvantages. In the workplace, the disclosure of HIV status can lead to the provision of supportive workplace accommodations (e.g., flexible work hours, less physical labor), appropriate vocational services, and increased access to support networks (Barkey, Watanabe, Solomon, & Wilkins, 2009). It can also effectively explain employment gaps (Maguire, McNally, Britton, Werth, & Borges, 2008). However, HIV disclosure at work can also have high costs. More broadly, in the context of work, chronic illnesses are often viewed negatively and dealt with insensitively (Reavley, Jorm, & Morgan, 2016), and HIV is no exception (Barkey et al., 2009; Worthington et al., 2012). Disclosing HIV status at work can indeed lead to workplace discrimination (Barkey et al., 2009; Kazathchikine, 2010; Worthington et al., 2012). Research has demonstrated negative attitudes about the employability of PLWH and resistance to

the provision of adequate workplace accommodations on the part of employers (Rao, Angell, Lam, & Corrigan, 2008; Werth, Borges, McNally, Maguire, & Britton, 2008; Worthington et al., 2012). In a study conducted by COCQ-SIDA among Canadian employers, 38% indicated that they would avoid hiring PLWH, citing concerns about PLWH's capacity to be productive and efficient at work alongside concerns about absenteeism. In that same study, 36% of the surveyed employers indicated that, if they were to become aware that someone had failed to disclose their HIV during the hiring process, they would feel disappointed, angry, and/or betrayed (COCQ-SIDA, 2009; as reported in Kazathchikine, 2010). That study further demonstrated that PLWH were likely to suffer workplace discrimination at the hands of their colleagues manifested as the endorsement of confidentiality breaches to inform colleagues of an employee's HIV status. Additionally, the study reported that, among participants who had previously worked with someone with HIV, 52% stated that person had been rejected by colleagues, 48% claimed that the colleague with HIV had been the subject of gossip and rumors, and 30% believed that their colleague had been the victim of harassment (COCQ-SIDA, 2009; as reported in Kazathchikine, 2010).

The effects of workplace discrimination are significant. Anticipated and enacted workplace discrimination has impeded the search for work, limited employment opportunities, and has been found to be related to a risk of employment loss (Maguire et al., 2008; Werth et al., 2008). In the workplace itself, perceived stigma has been found to reduce organizational commitment and organizational citizenship behavior while increasing organizational cynicism (Bashir, 2011). It also, expectedly, has inhibited the disclosure of HIV status at work, thus limiting access to adequate supports at work (Degroote et al., 2014; Maguire et al., 2008; Werth et al., 2008; Worthington et al., 2012).

Understanding disclosure experiences at work is important. Labor force participation by PLWH not only provides income for the infected professional but also contributes to psychological well-being and quality of life, as it provides structure in daily life, opportunities to connect socially with others, and a sense of independence and self-determination (Worthington et al., 2012). The health care sector in

the Netherlands is a large employment sector and is thus an appropriate context in which to study HIV status disclosure in the workplace. To our knowledge, all previous studies investigating the experiences of health care providers with HIV were conducted in Sub-Saharan Africa, where HIV is endemic.

Our study is the first to explore the workplace experiences of health care providers with HIV in a nonendemic European context. By focusing not only on disclosure versus concealment and the underlying motivations for disclosure and concealment, but also on the reactions of others, the impact of those reactions, and the ways in which negative reactions are coped with, we provide new insights on HIV in the workplace, namely within the health care sector, in a nonendemic context.

Methods

Study Design and Context

In this qualitative study, we explored the disclosure experiences of health care providers living with HIV in the Netherlands, the responses to disclosure received from colleagues and managers, and the impact of those responses. Our specific research questions were: (a) *What are the motivations of health care providers with HIV for disclosing or concealing their HIV status at work?* (b) *What kind of reactions to disclosure of HIV status at work have health care providers with HIV experienced?* (c) *What are the psychological impacts of HIV status disclosure at work for health care providers with HIV?* and (d) *How do health care providers with HIV cope with negative reactions to HIV status disclosure at work?*

We employed a general inductive approach that explicitly had no formal methodological orientation (Thomas, 2006). We set out to gain an understanding of the experiences of health care providers with HIV working in the Dutch health care sector such that the insights derived from our study could be used as input for improved health care workplace interactions, and thus, our methods were practice-driven rather than guided by a given methodological heritage (Thorne, 2011).

The context in which the study occurred was among health care providers with HIV working in

the Netherlands. As of May 2016, 18,866 PLWH, 99% of whom were adults, were enrolled as patients in specialized HIV care in the Netherlands. Of the 18,355 PLWH in care in 2015, 95% ($n = 17,909$) were on combination antiretroviral therapy, and of those, 93% ($n = 16,739$) had an undetectable viral load ([HIV Monitoring Foundation, 2016](#)). Over the years, improvements in life expectancy and quality of life have resulted in greater labor participation by PLWH. There are, to our knowledge, no data available on the number of health care providers with HIV working in the Netherlands, but the Dutch health care sector is relatively large, employing 1.42 million people in 2013 ([Central Bureau of Statistics, 2015](#)).

Ethical approval was provided by the Open University of the Netherlands' Faculty of Psychology and Educational Sciences (U2012/04530/NJA). No monetary compensation was provided for participation, but interview participants received a gift valued at approximately €10.

Sampling and Recruitment

Ten health care providers living with HIV and working in the Netherlands, including specialized nurses, nursing assistants, and a pharmacist, were recruited purposively via an advertisement on the Dutch HIV Association's website or via snowball sampling. After initially having responded to the advertisement or being contacted, potential participants were provided with verbal and written information about the purpose of the study and what an interview would entail. Confidentiality and the possibility to withdraw at any time were also discussed.

Data Collection

Single, face-to-face, semi-structured interviews of approximately 1 hour were conducted between September 2011 and March 2012 by a female postdoctoral researcher with extensive experience conducting qualitative research, particularly with PLWH. The interviews were conducted in Dutch at a location chosen by the participant, usually the participant's home or office, and no other people were present at the time of the interview. Interviews were always preceded by informed consent, guided by a structured protocol with follow-up probes, and

followed by a short survey measuring demographic and HIV-related characteristics. All interviews were recorded with a digital voice recorder and transcribed verbatim. The topics covered in the interviews were disclosure to colleagues, colleague reactions to disclosure, and the impact of those reactions. Translations of the interview questions are included in [Table 1](#).

Data Analyses

Data were processed thematically using QSR NVivo 8 (QSR International, Doncaster, Victoria, Australia). Each transcript was read while listening to its corresponding recording in order to identify themes and establish categories to which text fragments could be assigned. As coding occurred, thematic categories and subcategories were developed and connected to one another. The initial coding tree included the following parent nodes: reasons for disclosure, reasons for concealment, reactions to disclosure, impact of reactions, and coping. During coding, a decision trail was maintained using annotations and memos that indicated potential new insights and changes to the coding structure. As such, all emergent categories were documented, as were changes made to those categories, and the reasons for those changes. Analyses yielded the following themes: disclosure, concealment, positive reactions, negative reactions, consequences of positive reactions, consequences of negative reactions, and coping with negative reactions. After coding, the preliminary findings were presented to a group of PLWH working in the Dutch health care sector to assess congruence between findings and workplace experiences (i.e., a

Table 1. Interview Questions

Disclosure and concealment
How open are you about your HIV status at work?
Who at work have you told about your HIV?
What were your reasons for telling this person?
Who have you not told? Or are there people that you have not told?
Why did you choose not to tell this person?
Reactions to disclosure
How did the person you told about your HIV status at work react? (per disclosure target)
Consequences and coping with negative reactions
How did that reaction make you feel?
How did you deal with that particular (negative) reaction?

member check). The preliminary findings were also compared to research on employees in health care who were living with HIV infection. Selected quotes were translated to English and reviewed for originality of meaning by the first author, who is fully bilingual in English and Dutch.

Results

Participant Characteristics

Most participants were gay men ($n = 9$; 90%). One was a heterosexual woman. All were Dutch. Six lived in an urban center (60%). Ages ranged from 27 to 59 years, with a mean age of 46.0 years ($SD = 9.9$). Five had a bachelor's degree or more (50%), four had a high school diploma and some vocational training (40%), and one had high school or less (10%). Nine reported having contracted HIV through sexual intercourse (90%) and one participant was not sure how he had acquired HIV. Mean time since diagnosis was 9.0 years ($SD = 7.5$). Health care occupations included specialized nurses, nursing assistants, and a pharmacist. Places of work included general hospitals, a psychiatric hospital, nursing homes for the elderly, a group home for people with disabilities, and a pharmacy.

Disclosure at Work

The extent to which the health care providers with HIV included in this study disclosed their HIV status at work to employers, managers, and colleagues varied. Some reported making a conscious choice to be open about their HIV at work (three participants), while others made a conscious choice to conceal their HIV status (two participants). Others reported not explicitly hiding their HIV status, but at the same time, not being overtly open about it (two participants). In the words of one participant, "I would never deny it if people were to ask but I wouldn't go up to my new colleagues and say, 'I have to tell you something: I have HIV'" (Guido, age 47 years, nurse; please note that names have been changed to protect the identity of participants). Still others reported having previously been open at work, but not anymore (three participants): "I'm not going to tell people anymore. I don't tell anyone at all and if anyone asks, then I just say, 'What makes you think

that? Do I look like someone who has HIV?'" (Gabriel, age 51 years, nurse).

A number of reasons for disclosure and concealment at work were provided by participants. These are displayed in Table 2. Of those who opted to disclose at work, the motivation was sometimes self-focused and sometimes other-focused. An important self-focused reason was that disclosure could be cathartic: "It felt like the more open I was about it, the more I felt set free, and I became happier by, by just sharing it" (Frank, age 50 years, nurse). Disclosure was also reported to be motivated by expectations that disclosure would be positively received: "I don't feel like hiding it at work, in, let's say, my place of employment. We have lots of clients with HIV so it's pretty normal" (Stef, age 27 years, pharmacist). A similar reason for disclosure was that participants had observed positive responses when other PLWH disclosed: "There was another guy in my department who was also HIV-positive and he was open about it so I knew that it was a safe environment for me to talk about it" (Guido, age 47 years, nurse). An additional reason for disclosure was that proactively disclosing one's status could help to prevent negative responses. Michael explained that he told his colleagues, "So that all my colleagues would hear it from me, to prevent it from spreading through the hospital as gossip" (Michael, age 54 years, nurse). Some participants also claimed that disclosure should be used as a broader strategy to reduce HIV-related stigma:

The reason I told them was because, I'm annoyed by the, by the stigma that is linked to HIV and I thought that – I felt like I'm strong enough and I know where I'm at and what I stand for and I want to be open about it and that should be okay. (Gabriel, age 51 years, nurse)

A final reason for disclosing one's status at work in the health care sector was having been advised to disclose by a relevant health care provider such as a company physician who, in the Netherlands, functions to guide processes of employee absenteeism and reintegration.

Concealment at Work

Of the participants who opted to conceal their HIV status at work, two main reasons for concealment were

Table 2. Reasons for Disclosure and Concealment, Reactions From Others, Consequences and Coping

Reasons for disclosure	Reasons for nondisclosure
<ul style="list-style-type: none"> - Could be cathartic - Expect disclosure to be positively received - Observed positive responses - Proactively prevent negative responses - Reduce HIV-related stigma - Having been advised to disclose 	<ul style="list-style-type: none"> - Could lead to negative or stigmatizing reactions - Anticipated stigmatization - Observed negative responses to others - Previous negative experiences with disclosure - Having been advised to conceal - Disclosure is not relevant or necessary
Reactions to disclosure by others – positive	Reactions to disclosure by others – negative
<ul style="list-style-type: none"> - HIV status seen as a nonissue - Interest, support, and empathy - Confidentiality maintained 	<ul style="list-style-type: none"> - Other employees informed about HIV status - Restrictions placed on work duties - Difficulties acquiring work - Gossiped about at work - Hurtful and judgmental comments made
Personal consequences of negative reactions	Coping strategies for negative reactions
<ul style="list-style-type: none"> - Upset and taken aback - Anger - Resignation 	<ul style="list-style-type: none"> - Providing accurate information - Standing above the negative experience - Attributing negative response to ignorance - Seeking social support - Leaving job

provided. The first was that disclosure could lead to negative or stigmatizing reactions. In fact, anticipated stigma was a frequently cited reason for disclosure. Benjamin, for example, reported that he would feel comfortable disclosing a condition such as diabetes at work, but not his HIV status, “Because it really does have a certain stigma with a lot of people ... I’ve worked here for a really long time and I just don’t want to take the risk and tell and then have things change” (Benjamin, age 50 years, nursing assistant). Having observed negative responses to HIV was also cited as a reason for concealment:

I’m not going to tell them anymore because I’m, yeah, I’m scared of how my colleagues will react. And where does this come from? It comes from, for example, the fact that whenever a patient is admitted and he has HIV, then they immediately say, “You need to be careful, eh? He has HIV so be extra careful.” (Gabriel, age 51 years, nurse)

Additionally, some participants reported concealing at work because of their own personal negative experiences with disclosure in the past: “At my work, they don’t know. My colleagues don’t know because I had a horribly disastrous experience at [former employer]” (Sam, age 50 years, nurse).

Furthermore, some participants chose not to disclose at work because they had been advised by management to conceal:

I had a conversation with my boss there and, I mentioned it and she responded by saying, “Keep that to yourself. The people here – the employees – react at a more basic level. It’s difficult to explain but like education, understanding. They can react poorly to these kinds of things.” (Michael, age 54 years, nurse)

In short, avoiding negative reactions or stigma, be it anticipated, observed, or experienced, functioned as an important motivation for concealing HIV status at work by health care providers living with HIV.

Another main reason for concealment provided by participants was not related to stigma avoidance but rather to a kind of normalization of HIV. Quite a few participants indicated that they had not told their colleagues and employers about their HIV status because they felt it was not relevant or necessary.

I haven’t told anyone there. I’ve gotten to the point where, it’s part and parcel and, I don’t need – I don’t feel the need to talk about, to tell people ... I no longer have that need to talk about it with everyone. (Dana, age 39 years, nursing assistant)

Who am I accountable to? Accountability: what a word, eh? I mean do I really have to automatically tell them everything about me? If I have something, do I immediately have to tell my colleagues, I have this or that? No, I don't. (Leon, age 59 years, nurse)

Clearly, disclosure or concealment at work is very much a personal choice for health care providers with HIV and is motivated by a range of expectations and experiences. Of participants who had concealed or continued to conceal their HIV status at work, most reported that concealment could be quite difficult. Fears of being discovered or accidentally and unintentionally disclosing were reported. For example, Benjamin indicated that his HIV status “accidentally slipped out one time” (Benjamin, age 50 years, nursing assistant). He also spoke of having to make up stories in order to deal with questions about his medication: “Once I had a colleague say, ‘Did you just take an aspirin?’ so I said, ‘Yeah, I have a bit of a headache so I took an aspirin’” (Benjamin, age 50 years, nursing assistant). Sam similarly conveyed concerns about being discovered if he were to become ill as a result of HIV:

It's hard because I am stuck thinking, “What happens if I get sick?” And, yeah, how, how – see, you can get the flu or be home sick for a week and that doesn't make anyone suspicious but I could be worse. Let say I get pneumonia, which is unlikely, but you never know. I can't predict the future. But then I'd have to tell. I find that really difficult. (Sam, age 50 years, nurse)

Yet another participant retrospectively discussed the cognitive burden of concealment:

You only realize after the fact just how much energy it costs to live with a secret and that's especially the case when things start to shift and they get complicated because there comes a point when you can't remember who you've told and who you haven't told. Should I? Should I not? And then you end up with all sorts of unanswered questions and, and that costs so much energy and it makes you insecure. (Frank, age 50 years, nurse)

Positive Reactions and Their Impact

In our sample of health care providers with HIV whose colleagues knew they had HIV, a number of reactions were reported (see [Table 1](#)). Many reported positive experiences. Most frequently, participants spoke of colleagues and managers viewing their HIV status as a nonissue. In the words of Stef, colleagues responded “really nonchalant and open” (Stef, age 27 years, pharmacist). In some cases, participants said that colleagues and managers had initially reacted with some concern regarding the implications of HIV in the workplace, but that this quickly dissipated:

Basically, it was like there was a peak but that peak came and went really fast. So, what it comes down to is that, in the beginning, it was talked about and thought about a lot but that was, at a given moment, gone and nobody gave it anymore thought. (Isaac, age 33 years, nursing assistant)

In addition to this kind of normalized response to HIV, participants reported colleagues and managers responding to their HIV status with interest, support, and empathy. For example, Isaac indicated that his direct manager had shown an interest in learning more about HIV: “She said, ‘I don't know much about this so maybe you give me some information to read?’” (Isaac, age 33 years, nursing assistant). Isaac also spoke about how a higher-level manager had shown concern about the appropriateness of his employees' reactions: “He said, ‘How have your colleagues reacted?’ I said, ‘Yeah, fine.’ ‘Yeah,’ he said, ‘If that's not the case, you just let me know and I'll take care of it’” (Isaac, age 33 years, nursing assistant). Support and empathy from more direct health care colleagues was also reported: “They were really empathetic reactions. Yeah. Very supportive and also questions. And if there was room for it, also kind of some counseling” (Frank, age 50 years, nurse).

Lastly, some participants reported that, in cases of selective disclosure at work, they were pleased to see that confidentiality about their HIV status had been maintained. In the words of one health care provider with HIV who had only disclosed to one colleague, “Thus far, it's gone well because, for the rest, I haven't heard anything from anyone. I haven't

noticed anything so I think, up until now, she's kept her mouth shut" (Benjamin, age 50 years, nursing assistant).

In terms of the impact of positive interactions, participants generally felt that such responses were, and should be, normal, and that, as such, positive responses did not significantly impact their psychological or social well-being. Some health care providers with HIV did, however, convey that positive experiences at work made them feel comfortable in their work environment and that such positive experiences could compensate for the impact of negative responses to HIV status disclosure at work.

Negative Reactions to HIV Status

Although responses to HIV status at work were generally positive, health care providers living with HIV did report experiences whereby they felt that colleagues or management had reacted poorly upon discovering that they had HIV (see [Table 1](#)). For example, 2 of the 10 participants reported management wanting to inform employees about their HIV status due to perceived risks to employees and patients:

She [team leader] wanted to inform human resources and the management about my HIV status because I was a risk to the department for both patients and my colleagues. And I tried to explain that HIV can't be transmitted in normal social contact, but she wasn't so sure of that. And I told her that she couldn't do that, that she couldn't simply decide to tell others that I'm HIV-positive because it violates privacy laws. And she just got really angry. She said to me, "Well, I believe, in this situation, you are in no position to make demands." (Isaac, age 33 years, nursing assistant)

These same two participants also reported that their respective managers attempted to place restrictions on their work duties as a result of perceived risks:

I was basically removed from my position there ... I was allowed to stay in the department but I wasn't allowed to do any patient treatment or activities anymore, so basically it became an administrative job ... So, they didn't fire me.

Obviously, they couldn't, but they did make things so difficult that I could no longer take pleasure in my job. (Sam, age 50 years, nurse)

Another participant similarly reported that his manager had concerns about patient contact posing a risk for infection: "He asked me straight out. He said, 'Isn't that risky with your HIV?'" (Guido, age 47 years, nurse). Guido also reported difficulties acquiring work in the health care sector as a result of his HIV infection:

Every time I was invited for an interview and in that interview, I would openly tell them what was going on [HIV status] and every time I was second choice. And if that happens once, you think, "Well, too bad," but when it happens six times, you start to think, maybe next time I shouldn't tell them. (Guido, age 47 years, nurse)

In addition to involuntary disclosure and exclusion from work duties, some health care providers with HIV reported being gossiped about at work: "I told a few people thinking that they would keep it to themselves. I didn't say, 'You can't tell others,' I just assumed, but that didn't work. That was eventually told to others" (Gabriel, age 51 years, nurse). Along similar lines, hurtful and judgmental words were also reported: "At one point in time, she (colleague) just spat it out and said, 'Well, had I known you're HIV-positive, I wouldn't have taken this job'" (Frank, age 50 years, nurse).

Consequences and Coping With Negative Reactions

The impact of colleagues' and management's negative reactions to participants' HIV status varied across participants (see [Table 1](#)). Some reported being upset and taken aback by negative responses to their HIV status at work:

It hit me like a bomb. I was totally floored ... It was like I'd been shot down by some kind of projectile. Yeah, it felt really drastic ... and really, really, I basically, at that moment, didn't respond ... That evening, I was really upset ... I was very emotional and I couldn't put it in perspective. (Frank, age 50 years, nurse)

Others reported being angry. Regarding his employer's decision to disclose his status to his colleagues without permission, Sam said:

I was really angry about it because these are things that I can say myself. I am vocal enough to say it. And I would have rather figured out when – if the opportunity arose – and to whom I wanted to tell, because I had an order, priorities about who I wanted to tell. People that you get along with best, people that you also spend your free time with, I wanted to tell them first. (Sam, age 50 years, nurse)

Still others reported that negative interactions left them feeling depressive: “I felt really down. I felt really small” (Gabriel, age 51 years, nurse). For Gabriel, negative responses to his HIV status had also led to a sense of resignation:

And later I thought what difference is it going to make? Forget it ... I thought if they're like that, I can tell them but they won't do anything with the information anyhow and so there's no use in confronting them. (Gabriel, age 51 years, nurse)

In terms of coping with negative reactions, our data suggest that health care providers with HIV were most inclined to tackle negative reactions head on by providing accurate information about HIV and infection risks at work in the health care sector. One participant dealt with a colleague's concerns by sending information: “I sent her some information, like, ‘If you want to know anything or look anything up, check this out.’ Well, that seemed to really help her” (Benjamin, age 50 years, nursing assistant). Another simply explained the fact that he posed no risk to colleagues at work, “Well, my knowledge is sufficient that I could just explain it to them” (Guido, age 47 years, nurse). Others opted not to confront, but rather to stand above what they perceived to be negativity about HIV:

Eventually, I regained a kind of fighting spirit, like, “Go ahead, think that.” And, yeah, then you can stand above it, above the emotion, and it's your rational thought that takes over, like, well, you may have a problem but I don't. (Frank, age 50 years, nurse)

Indeed, many participants dealt with negative interactions at work by attributing them to ignorance: “That just has to do with too little knowledge and experience” (Gabriel, age 51 years, nurse).

Another way in which health care providers with HIV dealt with negative reactions at work was by seeking social support from other colleagues: “I asked her [a supportive colleague], ‘What am I supposed to do about this?’ ... She gave me a few really good tips ... And that really helped me to deal with this much quicker” (Frank, age 50 years, nurse). For two participants, coping with negative reactions to their HIV status at work entailed leaving their jobs. This was the case particularly when negative responses to HIV status came from employers or management. One participant waited until a good opportunity arose: “So I started looking. And, obviously, in health care, it's easier to get a new job. There are shortages everywhere” (Sam, age 50 years, nurse). The other resigned on the spot:

I said to her, “I quit! Whatever happens doesn't matter at all. It's not the end of the world and, I have an entire life in front of me and I just want to be happy.” I thought to myself, “Sod off!” (Isaac, age 33 years, nursing assistant)

Discussion

We advance the literature by presenting unique findings on workplace disclosure of HIV status and its consequences for health care providers with HIV in the Netherlands. Specifically, we explored motivations for and against disclosure at work, reactions from colleagues and managers, the impact of negative reactions, and how health care providers with HIV coped with negative responses at work.

Disclosure or Concealment at Work

The findings indicated that decisions to disclose or conceal at work were motivated by various expectations and experiences. Health care providers living with HIV reported disclosing to colleagues because they felt the need to share their secret (emotional catharsis), they had expectations that disclosure would be positively received, they had observed positive reactions to other disclosures about HIV, they wanted

to be proactive and prevent negative reactions, they wanted to reduce HIV-related stigma, and they had been advised to disclose their status by relevant others, such as management. Reasons for concealing HIV status at work included fear of negative reactions (anticipated stigma), observed negative reactions to others (observed stigma), previous negative experiences with disclosure (enacted stigma), having been advised to conceal, and believing that disclosure was not relevant or necessary. These findings were in line with research on HIV status disclosure in the workplace and beyond (Chaudoir et al., 2011; Obermeyer et al., 2011; Stutterheim, Shiripinda, et al., 2011). For example, in a study investigating HIV disclosure at work in a small sample of Belgian PLWH (Degroote et al., 2014), participants reported disclosing because they did not want to keep their HIV status secret, and concealing because they feared discrimination and gossip and because they expected to be advised by their superiors to keep their HIV status a secret. Similarly, Worthington and colleagues (2012), in their review of the literature on labor force participation by PLWH more generally, stated that many PLWH concealed their HIV status at work to protect themselves from negative attitudes and hurtful responses. Further, in a study conducted with PLWH in the United States (Bairan et al., 2007), participants advised against disclosing at work as this could lead to job loss or difficulties finding work. They also indicated that, often, HIV status was not relevant to the work environment and thus did not need to be disclosed. Also in health care contexts, research has indicated that disclosure at work is not considered necessary. Aultman and Borges (2011), who investigated U.S. medical student attitudes toward HIV disclosure in health care settings, reported that, upon considering the possibility that health care professionals could have HIV—something they had not previously considered—participants claimed that patient safety and the use of infection control procedures were sufficiently emphasized, thus making disclosure to patients, colleagues, or employers unnecessary.

It was interesting that one of the reasons for disclosure given by participants in our study was the desire to be proactive and prevent negative reactions by circumventing possible third-party disclosure. The literature has indicated that this is, indeed, wise. In a large-scale study with PLWH across five coun-

tries, third-party disclosure was found to be associated with greater regret than self-disclosure (Henry et al., 2015), and in other research (Chaudoir, 2009), negative disclosure experiences were associated with concealment 6 months later. Also, fears of “being discovered” at work and the corresponding cognitive burden of concealment reported by participants in our study have been documented in the extensive literature on concealing stigmatized identities (Chaudoir et al., 2011; Pachankis, 2007) and in studies on disclosure or concealment at work (Braveman, Levin, Kielhofner, & Finlayson, 2006). For example, in a grounded theory study with 93 PLWH living in the United States (Maguire et al., 2008), participants reported anxiety about concealing and hypervigilant behaviors to maintain concealment at work.

Reactions to HIV Status Disclosure at Work

Our findings further showed that disclosure at work on the part of health care providers living with HIV could be met with both positive and negative reactions. Positive reactions included colleagues viewing HIV as a nonissue, thus reflecting a normalization of reactions to HIV status disclosure; sincere interest in one’s well-being, social support provision, and empathy; and maintained confidentiality. In terms of the impact of positive interactions, participants generally felt that such responses were, and should have been, normal, and that as such, did not significantly impact their psychological or social well-being. Some participants did, however, convey that positive experiences at work made them feel comfortable in their work environments and compensated for negative responses to HIV status disclosure at work. Negative reactions to HIV status at work included management unnecessarily wanting to inform other employees, restrictions being placed on work duties, difficulties acquiring employment, gossip, and hurtful or judgmental comments from colleagues. Similar positive and negative reactions to HIV status disclosure at work have been documented, but not among health care providers with HIV. For example, in the study by Degroote and colleagues (2014), positive disclosure experiences at work included experiencing no professional changes and being met with greater understanding. Regarding negative responses, reviews of HIV and work by Braveman and colleagues (2006) and by Worthington

and colleagues (2012) reported involuntary disclosure or breaches of confidentiality about HIV status from employers to colleagues. This is unsurprising given findings from studies on employers' attitudes toward PLWH employees. For example, in Rao and colleagues' (2008) study of employers' attitudes about PLWH in Hong Kong, Beijing, and Chicago, employers reported that their employees would have concerns about working with someone with HIV and that they felt an obligation to tell employees if they were considering hiring a PLWH. They also expressed concerns about the impact on clientele (e.g., patients) and voiced an intention to change work duties to limit contact with clientele, which we also found in our study.

Consequences and Coping with Negative Reactions

Further, our findings indicate that negative disclosure experiences at work faced by health care providers living with HIV had substantial negative impact, often due to the unexpected nature of the negative reactions. Participants reported being upset, taken aback, angry, feeling depressive symptoms, and experiencing a sense of resignation. This was in line with Maguire and colleagues (2008), who reported that participants in their study felt angry and frustrated about a lack of understanding and knowledge about HIV in the workplace. To deal with these negative emotions, the participants in our study responded by providing accurate information about, among other things, risks of infection (confrontation), by standing above the negative experience, by attributing negative responses to ignorance, by seeking social support, and, in some cases, by leaving their jobs. PLWH in the Maguire and colleagues (2008) study also reported asserting themselves and their rights when confronted with negative reactions, sometimes to the extent of taking legal action.

Implications and Recommendations

Clearly, our findings indicate that efforts to improve the workplace experiences of PLWH may be beneficial, likely not only for PLWH working in the health care sector but also for PLWH working in other sectors. We feel that efforts to improve the workplace experiences of PLWH can best be done

via theory- and evidence-based interventions that target both PLWH and their work environments.

Based on our findings and current literature on HIV in the workplace, we recommend specialized vocational counseling services for PLWH (Degroote et al., 2014; Worthington et al., 2012). Such counseling could provide guidance with respect to disclosure decisions (Maguire et al., 2008; Worthington et al., 2012). We recommend that these services emphasize that disclosure of HIV status at work is a choice, even in the health care sector (Chaudoir et al., 2011; Henry et al., 2015). Research on the disclosure of stigmatized identities such as HIV has shown that disclosure should be freely chosen and was likely beneficial only when it elicited social support and alleviated psychological stress (Chaudoir et al., 2011; Stutterheim, Bos, et al., 2011). If disclosure to colleagues and employers is not likely to generate social support or reduce psychological stress, it may be more advantageous to conceal at work, particularly when the potential costs of disclosure at work are high and when sources of support and a connection with similar others is available outside of the workplace (Stutterheim, Bos, et al., 2011).

Understanding and talking about potential costs and benefits of disclosure at work in a safe and confidential counseling setting is, thus, likely to be beneficial. In that context, it may be advantageous for nurses working in HIV care to prioritize an exploration of motivations for wanting to disclose or conceal HIV status at work with all working PLWH, including those working in health care, as these can impact disclosure outcomes. According to Chaudoir and colleagues (2011), motivations for disclosure could be delineated as either approach goals (obtaining positive outcomes; e.g., strengthening an important relationship) or avoidance goals (avoiding negative outcomes; e.g., avoiding conflict), and people with approach goals were more likely to benefit from a disclosure event. Additionally, Chaudoir and Quinn (2010) have shown that people who disclose for the sake of both themselves and others (ecosystem motivations), rather than only themselves (egcosystem motivations) tended to have more positive disclosure experiences. Thus, we recommend counseling efforts that explore PLWH's reasons for wanting to disclose in terms of whether the reasons are ecosystem or

ecosystem motivations and whether the individual is driven by approach or avoidance goals, accompanied by guidance on how to set approach goals and reframe avoidance goals, while considering the benefits of disclosure for themselves and others.

Additionally, given the knowledge that how disclosure happens impacts how others react (Chaudoir et al., 2011), we recommend providing PLWH with opportunities to safely role-play disclosure at work (Maguire et al., 2008; Werth et al., 2008) such that, should they want to, they are better prepared to disclose and deal with possible negative responses. Receiving feedback on how a given disclosure approach is likely to be received (Maguire et al., 2008) and troubleshooting how to deal with negative responses (Werth et al., 2008) are likely to lead to more positive disclosure experiences at work, or at least can buffer the negative impact of poor reactions to disclosure.

Further, counseling efforts can also work on building resilience and developing advantageous coping skills should the response to disclosure be negative. Maguire and colleagues (2008) recommended using strengths-based approaches that “seek to explore previously established patterns of coping, identifying the degree to which these approaches have benefited the client in the past” (p. 80). Along similar lines, Werth and colleagues (2008) recommended developing coping skills more generally, not specifically related to dealing with possible negative responses to HIV disclosure (i.e., stigma), as, they claimed, people who were confident in their abilities to deal with difficult situations were more likely to overcome barriers, thus impacting how they employed personal agency to develop their careers despite possible workplace discrimination.

Clearly, empowering PLWH to make informed choices regarding disclosure or concealment in the workplace, assisting PLWH to prepare for disclosure should that be their choice, and developing resilience and coping skills are important. These efforts can be further strengthened by services that inform PLWH working in, and beyond, the health care sector about their rights in the workplace (Braveman et al., 2006; Degroote et al., 2014). There is significant national, European, and international legislation protecting the rights of PLWH that PLWH can lean on should violations to their rights occur at work (Pereira, 2010). Knowing that protections exist and receiving

support from, for example, HIV service organizations, in applying protections can also contribute to improved workplace experiences for PLWH in both the short and long term (Li et al., 2007).

Evidently, improvements in workplace experiences and reductions in stigma in the workplace cannot solely be driven by proactive and resilient PLWH who take a stand and pave the way for inclusive and nondiscriminatory workplaces. Efforts within health care organizations that make workplaces safe for PLWH are equally important.

In our view, the most obvious starting point is the development, implementation, and application of comprehensive, well-structured workplace policies and structures that are inclusive, nondiscriminatory, and supportive of HIV issues (Bos, Pryor, Reeder, & Stutterheim, 2013; Worthington et al., 2012). In this regard, clear position statements on confidentiality, benefit structures, and reasonable accommodations, as well as on inclusion and discrimination, are likely to reduce anticipated stigma and, at least in part, alleviate concerns about disclosure (Worthington et al., 2012). Similarly, explicit policies indicating that employees are not required to divulge private medical information can relieve the burden of concealing HIV status should PLWH choose not to disclose at work (Pachankis, 2007).

However, creating safe workplaces for PLWH requires more than the creation of supportive policy and structures. Our findings indicated that most of the negative reactions experienced by our participants came directly from colleagues and superiors. It is, therefore, paramount that colleagues and managers be targeted. To this end, we recommend initiatives that seek to increase knowledge on the basics of HIV, including how it is transmitted, its course, and its treatment (Maguire et al., 2008). Particularly in the context of health care, it is also important to convey information specifically relevant for health care providers such as information on occupational risks, infection prevention measures, and post-exposure prophylaxis (Pisal et al., 2007).

Additionally, we recommend providing colleagues and managers with a nonjudgmental environment in which they can reflect upon and appraise their own thoughts, feelings, and attitudes toward PLWH in the workplace. This is important given literature showing that simply trying to suppress thoughts in

the form of, for example, stereotypes, is ineffective (Paluck & Green, 2009). It is, therefore, better to voice and then appraise the validity of one's ideas about HIV and PLWH. A reflective exercise is also important in light of Aultman and Borges' (2011) finding that medical students had not even considered that a colleague could have HIV. In that context, we also recommend the implementation of in-person or vicarious contact interventions (Pettigrew & Tropp, 2006) that normalize the notion of employing or working alongside PLWH (Rao et al., 2008) and that focus on generating empathic and accepting attitudes about PLWH as colleagues and employees (Batson et al., 1997). In doing so, it would be beneficial to outline how negative responses to HIV disclosure impact PLWH (Batson et al., 1997) and how even speaking more generally about HIV in a negative manner at work can have "an insidious, undermining effect even in the absence of direct discrimination" (Quinn & Chaudoir, 2009, p. 647).

Given the claim by Braveman and colleagues (2006) that struggles faced by PLWH in the workplace, including discrimination, are similar to the struggles experienced by people with other forms of chronic illness, we suggest embedding HIV-related stigma reduction efforts into broader diversity and inclusivity efforts, particularly in low prevalence locales such as Western Europe. A recent meta-analysis of 40 years of research on diversity training (Bezrukova, Spell, Perry, & Jehn, 2016) indicated that the effects of diversity training were greater when training was conducted over a significant period of time, focused on awareness and skills development, and complemented by other diversity initiatives.

In addition to the development and implementation of organization policies, initiatives, and training to reduce workplace discrimination of PLWH, we contend that it is imperative to also address systemic issues that create employment barriers and discrimination (Maguire et al., 2008; Werth et al., 2008) and to advocate for the creation of supportive structural conditions that promote the equal treatment of PLWH in the workplace (Bos et al., 2013). In doing so, it is important to be cognizant that HIV status may layer with other forms of stigma and marginalization associated with gender, sexual orientation, education attainment, and socioeconomic status (Henry et al., 2015; Stutterheim et al., 2016).

Conclusion

Fundamentally, the creation of safe workplaces for PLWH working in and beyond the health care sector via the promotion of positive reactions to disclosure and the reduction of workplace discrimination and stigma is a matter of not only social justice but also economic justice (Smart Richman & Hatzenbuehler, 2014). We hope that the study reported here has, by outlining workplace experiences of health care providers with HIV and the impact of those experiences, served to further the fundamental goal of social justice. At the same time, it is important to be cognizant of the limits of our study, which was a small-scale qualitative study reflecting the experiences of 10 PLWH working in the health care sector. We recommend that future research investigate disclosure and concealment, positive and negative reactions, consequences, and coping quantitatively and across sectors. Specifically, we recommend future research to explore the actual content of disclosure events as well as mediating processes through which disclosure impacts long-term psychological, social, and work outcomes.

Key Considerations

- Motivations for disclosure or concealment of HIV status should be explored when counseling people living with HIV (PLWH) working in the health care sector on whether to disclose their HIV status at work.
- Counseling should emphasize that disclosure of HIV status at work is a choice and discuss the potential costs and benefits of disclosure at work.
- Efforts to support PLWH working in the health care sector should focus on developing coping skills and building resilience.
- Health care organizations should make workplaces safe for PLWH through inclusive workplace policies and structures, initiatives that increase HIV knowledge, and efforts to enhance contact between PLWH and others.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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